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Problems in functioning from the patient perspective using the International Classification of Functioning, Disability and Health (ICF) as a reference

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SUMMARY We conducted a qualitative, multicenter study using a focus group design to explore the lived experiences of persons with any kind of primary sleep disorder with regard to functioning and contextual factors using six open-ended questions related to the International Classification of Functioning, Disability and Health (ICF) components. We classified the results using the ICF as a frame of reference. We identified the meaningful concepts within the transcribed data and then linked them to ICF categories according to established linking rules. The six focus groups with 27 participants yielded a total of 6986 relevant concepts, which were linked to a total of 168 different second-level ICF categories. From the patient perspective, the ICF components: (1) Body Functions; (2) Activities & Participation; and (3) Environmental Factors were equally represented; while (4) Body Structures appeared poignantly less frequently. Out of the total number of concepts, 1843 concepts (26%) were assigned to the ICF component Personal Factors, which is not yet classified but could indicate important aspects of resource management and strategy development of those who have a sleep disorder. Therefore, treatment of patients with sleep disorders must not be limited to anatomical and (patho-)physiological changes, but should also consider a more comprehensive view that includes patient's demands, strategies and resources in daily life and the contextual circumstances surrounding the individual.

KEYWORDS focus groups, ICF, patient perspective, qualitative study, sleep disorders, WHO

INTRODUCTION

Sleep disorders, whether primary or secondary, are associated with a wide range of functional impairments that may be associated with activity limitations and participation restrictions (Verster *et al.*, 2008). Sleep disorders have associated negative consequences on work performance (Daley *et al.*, 2009; Sivertsen *et al.*, 2009; Sjosten *et al.*, 2009) and driving (Pandi-Perumal *et al.*, 2006), which can lead to indirect public health costs. Therefore, a systematic and comprehensive understanding of the impact of sleep disorders on functioning is important to adequately recognize, optimally manage and treat sleep disorders (Colten and Altevogt, 2006).

For the World Health Organization (WHO), functioning and the ability to participate in everyday life can be understood not only as a mere consequence of disease and its treatment, but also within the context of the person that

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may differ greatly depending on that person's private and societal background (WHO, 1993). This would imply that the biological, psychological, social and environmental aspects of everyday life must be taken into account to have a comprehensive perspective of health.

Qualitative methodology provides the possibility to explore the perspective of those who experience the disease (e.g. patients; Kvale, 1996). Compared with quantitative methodology, the qualitative approach promises a greater openness to unexplored concepts or phenomena (Patton, 1990), and focuses on how people understand and interpret their social worlds (Hayhow and Stewart, 2006). Qualitative methods are increasingly accepted in health research and health-related sciences (Giacomini and Cook, 2000; Mays and Pope, 2000).

Qualitative methods in sleep medicine have been applied in the nursing field (Crew, 2006; Dickerson and Kennedy, 2006; Hsu *et al*., 2009; Johansson *et al*., 2007; Lee *et al*., 2007), pediatrics (Kennedy *et al*., 2007; Tse and Hall, 2008) and social sciences (Henry *et al*., 2008). One study applied focus group methodology to explore the lived experience of insomnia, and found evidence on the importance of relationships with significant others and health professionals (Carey *et al*., 2005). Considering the complexity and high burden associated with sleep disorders, qualitative research in the field of sleep medicine is generally scarce. Moreover, qualitative investigations around the variety of problems in functioning in persons with sleep disorders are lacking in the literature.

The aim of this study is to determine relevant aspects of functioning as well as relevant contextual environmental and personal factors from the patient perspective using qualitative methodology.

MATERIALS AND METHODS

Design

We conducted a multicenter qualitative study using focus group interviews as part of a larger project on the development of International Classification of Functioning, Disability and Health (ICF) Core Sets for sleep disorders. This study was one of the four preparatory studies of the project to gather information about the relevance of functional problems in people with sleep disorders (Stucki *et al*., 2008). The study was approved by the responsible Ethics Committee for each study center, and was performed in accordance with the Declaration of Helsinki.

Participants

Patients from three sleep centers were recruited by convenience sample. In order to obtain a comprehensive picture of the whole continuum of clinical care (i.e. maximum variation; Patton, 1990), patients of any etiopathology (first contact, control after first contact/polysomnography, under treatment, and chronic) were included. Maximum variation in the sample means that we aim to explore the broadest and diversified range of possible accounts of living with different sleep disorders, rather than making a comparative account of different diagnostic groups.

Individuals were included in the study if they: (1) had a diagnosis of a primary sleep disorder according to the 2nd edition of the International Classification of Sleep Disorders; (2) were older than 18 years; (3) spoke the German language; (4) had been attested to be sane (compos mentis) and capable of making decisions by the discretion of the investigator or health professional; (5) had been informed of the purpose and rationale of the study, and both had been understood; and (6) had signed the patient consent form. Individuals with significant cognitive impairment or whose main diagnosis is a major psychiatric or psychological disorder were excluded. Given that an ICF Core Set for depression has also been developed (Cieza *et al*., 2004), we ensured that all participants included in the study had a sleep disorder as the primary problem.

Sample size

The sample size was determined by calculating the saturation (Patton, 1990). Saturation refers to the point during data gathering when the linking of the qualitative data of two consecutive focus groups revealed no more than five additional new concepts compared with previous focus groups (Depoy, 1998; Krueger and Casey, 2000).

Materials

The ICF adopted by the WHO in 2001 (WHO, 2001) was used as a reference to analyse the data. The overall aim of the ICF classification is twofold: to offer a common framework for all health professions based on the bio-psycho-social perspective; and to provide a unified and standard language for the description of health and health-related domains (WHO, 2001).

The ICF classification distinguishes functioning into five components, namely (1) Body Functions and (2) Body Structures; (3) Activities & Participation; (4) Environmental Factors; and (5) Personal Factors. Each component consists of several chapters, with hierarchical ICF categories as the units of classification (WHO, 2001). The ICF components make up more than 1400 ICF categories, with the exception of Personal Factors, which has not yet been classified. Each ICF category is assigned an alphanumeric code – a letter that refers to the components of the classification (b: Body Functions; s: Body Structures; d: Activities & Participation and e: Environmental Factors) and is followed by a number or numbers starting with the chapter number (one digit) and followed by the second-level specification (three digits) and, when applicable, further third- and fourth-level specification.

An established topic guide was previously used and developed by our group (Kirchberger *et al*., 2009; Stamm *et al*., 2007). This guide describes how to prepare and perform focus group sessions using the open-ended questions. The following

open-ended questions based on the ICF components were used.

(1) If you think about your body and mind, what does not work the way it is supposed to? [Body Functions]
(2) If you think about your body, in which parts are your problems? [Body Structures]
(3) If you think about your daily life, what are your problems? [Activities & Participation]
(4) If you think about your environment and your living conditions, what do you find helpful or supportive? [Environmental Factors – facilitators]
(5) If you think about your environment and your living conditions, what barriers do you experience? [Environmental Factors – barriers]
(6) If you think about yourself, what is important about you and the way you handle your disease? [Personal Factors]

Data collection

Focus group interviews were conducted in a non-directive manner by the same moderator (BK), who is experienced in working with the ICF and in conducting patient interviews. The moderator has not been involved in any medical treatment of the focus group participants prior to the study. All focus group interviews were conducted according to standardized guidelines to include open-ended questions, and instructions such as introduction, procedure of the session and other technical aspects.

Data analysis

Qualitative analysis

The meaning condensation procedure (Kvale, 1996) was used as the basis of the qualitative analysis of data. In the first step, the transcripts of the focus groups were screened to get an overview of the collected data. In the second step, the data were divided into 'meaning units' and the theme that dominated a meaning unit was determined. A meaning unit was defined as a specific unit of text with either a few words or a few sentences with a common theme (Karlsson, 1995). A meaning unit division does not follow linguistic grammatical rules. The text was divided where the researcher discerned a shift in meaning (Kvale, 1996). Finally, the concepts contained in the meaning units were identified. A meaning unit could contain more than one concept.

Linking to the ICF

The identified concepts were linked to the categories of the ICF based on established linking rules (Cieza *et al.*, 2002, 2005), which allow concepts to be linked to the ICF categories in a systematic and standardized way. There were some important concepts that cannot be classified within the ICF, namely personal factors ('PF'), health condition ('Hc'), concepts that relate to the ICF but cannot be assigned a particular component or code ('Nd'), and concepts outside of the ICF framework ('Nc').

In order to avoid possible bias (improve reliability) between two linkers, calibration linking was performed by two different health professions who are trained in the ICF linking. We calculated the frequency of linked categories for the different focus groups and the overall frequency that each category has been identified.

Quality of data

Several strategies were used to improve and verify the trustworthiness of the qualitative data. First, data triangulation was applied to ensure the comprehensiveness of data by using two data analysts (investigator triangulation, multiple coding; Barbour, 2001; Denzin, 1978). Second, continuous data analysis was used according to Pope and Mays (2000). Third, reflexivity was assured by conducting a research diary for the documentation of memos concerning the design, data collection and analysis of the study. Fourth, clear exposition was used establishing guidelines for conducting the focus groups (including open-ended questions), verbatim transcription and implementing the linking rules (Cieza *et al.*, 2002, 2005). By using these strategies, we are confident that an appropriate account of the methods of data collection and analysis was assured.

RESULTS

Description of the focus groups

A total of 27 patients participated in six focus groups with a mean age of 48.96 years. The majority of the participants were female (59.3%). Of the 27 patients, diagnoses of a primary sleep disorder specifically included four insomnia, 10 sleep-related breathing disorders, nine hypersomnias of central origin, two sleep-related movement disorders, and two with multiple sleep diagnosis.

The progress of saturation is displayed in Fig. 1.

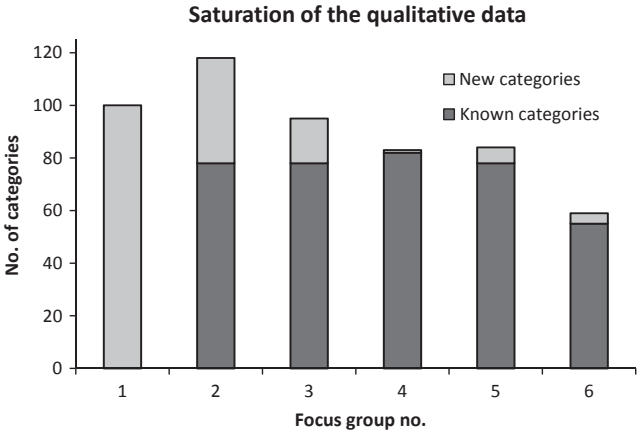

Figure 1. Saturation of the qualitative data.

Qualitative analysis and linking

A total of 6986 relevant ICF linkings were performed in the focus groups and linked to 168 different second-level categories. Out of these 168 categories, we identified 53 (31.5%) categories belonging to Body Functions, 57 (33.9%) categories belonging to Activities & Participation, and 48 (28.6%) categories belonging to Environmental Factors. Ten (6%) categories belonged to Body Structures. For those concepts that were not classified but linked, 1844 (26.4%) belonged to the ICF component Personal Factors, 323 (4.6%) were coded as 'Nd', 157 (2.2%) as 'Hc', and 71 (1%) were 'Nc'.

Body functions

Table 1 shows the second-level categories identified for the component Body Functions. The top five categories most frequently mentioned in each focus group are b134 Sleep functions (486 linkings), b130 Energy and drive functions (375 linkings), b126 Temperament and personality functions (175 linkings), b140 Attention functions (46 linkings), and b455 Exercise and tolerance functions (38 linkings). Below is a quote illustrating some of these categories by an individual with narcolepsy (related concepts in italics and linking examples in brackets):

> ''…the *tiredness* [b1300 Energy level], and sometimes *the capacity to concentrate* [b140 Attention functions]. Especially when I have one of these *sleep attacks* [b134 Sleep functions], I am definitely *more irritable* [b1263 Psychic stability]…''

Body structures

Table 2 shows the second-level categories identified for the component Body Structures.

The ICF category s750 Structure of lower extremity (mentioned in four focus groups, 14 linkings) and s710 Structure of head and neck region (mentioned in three groups, three linkings) were considered.

Activities & participation

Table 3 shows the second-level categories identified for the component Activities & Participation.

The top five categories identified and mentioned in each of the focus groups are d850 Remunerative employment (212 linkings), d920 Recreation and leisure (190 linkings), d230 Carrying out daily routine (106 linkings), d415 Maintaining body position (50 linkings), and d240 Handling stress and other psychological demands (50 linkings).

Typical quotes from the focus groups are exemplified by the following patient with a severe chronic insomnia that he reported to have over the past 15 years and which severely impaired his ability to work:

> ''…I *don*'t work 100% any more [d850 Remunerative employment], that is just not possible any more.''

A person with sleep apnea elaborates on work as follows:

> ''The *work,* [d850 Remunerative employment] I still take that so seriously as to say: there you just have to, *you have to function* [Pf], with *the other things* [nd] you don't have to necessarily.''

Or in interrelation with d240 Handling stress and other psychological demands by a person with narcolepsy:

> ''But it might happen, that I have *crisis* [b134 Sleep functions] *during work* [d850 Remunerative employment], and *this does stress me out* [d2401 Handling stress].''

Another quote by another patient with a serious case of insomnia in our sample:

> ''…I then pay for it *in the evening* [nc] in *leisure time with friends* [d9205 Socializing], then, I am not really any more, uh, always *prepared to be receptive* [b126 Temperament and personality functions].''

With regard to d415 Maintaining a body position the following patient with restless legs syndrome (RLS) describes it as follows:

> ''I once *fell from a chair* [d4153 Maintaining a sitting position] because *I fell asleep* [b134 Sleep functions].''

A newly-diagnosed patient with sleep apnea summed it up for the group:

> ''But I believe the bottom line is: *we all suffer in everyday life* [d230 Carrying out daily routine].''

Environmental factors

Table 4 shows the second-level categories identified for the component Environmental Factors.

The categories occurring most frequently and in each focus group are e310 Immediate family (168 linkings), e110 Products or substances for personal consumption (149 linkings), e410 Individual attitudes of immediate family (96 linkings), e580 Health services, systems and policies (85 linkings), and e355 Health professionals (84 linkings).

For example, one person with insomnia put it this way, when stressing the impact of his sleep disorder on his social environment:

> ''…everything is afflicted by that: *the kids* [e310 Immediate family], *the wife* [e310 Immediate family], *the colleagues* [e325 Acquaintances, peers, colleagues, neighbors and community members]…''

A woman with idiopathic hypersomnia quoted the support she receives from her husband as follows:

> ''…I just *attend the family until 17:30h* [d760 Family relationships] and then my *husband comes in and takes over that part* [e310 Immediate family]''

Environmental factors may be facilitators, but they may also be perceived to be barriers, as expressed in the following quote by a male patient with sleep apnea:

> ''…and I also have *a very understanding wife* [e410 Individual attitudes of immediate family members – Facilitator], and therefore…; *the first wife got a divorce* [d7701 Spousal relationships]…firstly because of the *snoring* [b450 Additional

Table 1 Fifty-three second-level categories of component *Body Functions* (b): number of focus groups in which ICF categories (second-level) were mentioned by the participants; number of linkings across all focus groups

Body functions		*N**	*N*†
b110	Consciousness functions	5	86
b114	Orientation functions	4	6
b122	Intellectual functions	1	3
b126	Temperament and personality functions	6	175
b130	Energy and drive functions	6	375
b134	Sleep functions	6	486
b140	Attention functions	6	46
b144	Memory functions	4	21
b147	Psychomotor functions	4	14
b152	Emotional functions	5	93
b156	Perceptual functions	5	19
b160	Thought functions	5	30
b164	Higher-level cognitive functions	4	40
b167	Mental functions of language	2	3
b180	Experience of self and time functions	5	35
b210	Seeing functions	4	20
b215	Functions of structures adjoining the eyes	5	15
b220	Sensations associated with the eye and adjoining structures	3	6
b230	Hearing functions	4	10
b240	Sensations associated with hearing and vestibular functions	2	11
b250	Taste functions	1	1
b260	Proprioceptive functions	1	2
b265	Touch functions	3	3
b270	Sensory functions related to temperature and other stimuli	3	7
b280	Sensations of pain	5	63
b330	Fluency and rhythm of speech	1	4
b410	Heart functions	3	7
b415	Blood vessel functions	1	2
b420	Blood pressure functions	1	4
b430	Hematological system functions	1	2
b435	Immunological system function	1	1
b440	Respiration functions	3	21
b445	Respiratory muscle functions	1	1
b450	Additional respiratory functions	5	16
b455	Exercise tolerance functions	6	38
b460	Sensations associated with cardiovascular and respiratory functions	2	6
b515	Digestive functions	1	1
b530	Weight maintenance functions	5	30
b535	Sensations associated with the digestive system	1	5
b620	Urination functions	1	1
b640	Sexual functions	1	1
b710	Mobility of joint functions	2	2
b715	Stability of joint functions	1	1
b730	Muscle power functions	5	6
b735	Muscle tone functions	4	79
b755	Involuntary movement reaction functions	1	1
b760	Control of voluntary movement functions	4	8
b765	Involuntary movement functions	3	5
b770	Gait pattern functions	1	1
b780	Sensations related to muscles and movement functions	3	8
b830	Other functions of the skin	3	7
b840	Sensations related to skin	1	1
b850	Functions of hair	2	2

*Number of focus groups ($N = 6$) mentioning the respective ICF category.
†Number of linkings across all focus groups ($N = 6$).

respiratory functions], and secondly because *she didn*'t have the nerves [e410 Individual attitudes of immediate family members – Barrier].''

The second-level category e110 Products or substances for personal consumption comprises both e1100 Food and e1101 Drugs as subcategories on the third level.

Table 2 Ten second-level categories of component *Body Structures* (s): number of focus groups in which ICF categories (second-level) were mentioned by the participants; number of linkings across all focus groups

Body structures		*N**	*N*†
s110	Structure of brain	1	2
s220	Structure of eyeball	1	1
s310	Structure of nose	2	2
s320	Structure of mouth	1	2
s710	Structure of head and neck region	3	3
s720	Structure of shoulder region	1	8
s730	Structure of upper extremity	2	14
s750	Structure of lower extremity	4	11
s760	Structure of trunk	1	3
s770	Additional musculoskeletal structures related to movement	1	1

*Number of focus groups ($N = 6$) mentioning the respective ICF category.
†Number of linkings across all focus groups ($N = 6$).

One example was mentioned by a woman living with insomnia:

''…for the past half year *I am eating chocolate* [e1100 Food], and I have the feeling that I am *getting myself the energy* [b130 Energy functions] through *food* [e1100 Food – facilitator].''

More frequently, however, medications were an issue, perceived to be both a facilitator and barrier. One person with narcolepsy elaborated:

''I don't take any *medication* [Pf], and I don't want to as long as possible, because they *don*'t do me any good [e1101 Drugs – barrier].''

A patient with severe RLS stated:

''…at night, that would be unthinkable *without the two pills* [e1101 Drugs – facilitator], unthinkable!''

What concerns the categories representing the health system, many patients described their negative experiences when they had to describe their health condition:

''…I went to see many *doctors* [e355 Health Professionals], who just didn't know it.''

''…they sent me to the psychiatrist and *the psychiatrist, fortunately, he asked me after an hour, what I wanted* [e450 Attitudes of health professionals].''

''…when I went to *the sleep clinic* [e580 Health services] for the first time […], *he wanted to put it out like I was simulating* [e450 Attitudes of health professionals].''

Personal factors

A large part of the meaningful data identified was coded to belong to the component Personal Factors.

We were able to broadly distinguish between Personal Factors as person characteristics that remain unchanged during the trajectory of a health condition, and those strategies that persons with sleep disorders develop especially to cope with their disorder. These could be strategies that patients developed as they undergo their treatment regimen. This theme was expressed in the following quote by a participant with narcolepsy:

''I strongly *differentiate between free time and work* [Pf], because I currently use [*medication*] [e1101 Drugs] for *work* [d850 Remunerative employment] only.''

Relating to the aspect of visibility of sleep disorders and ensuing problems in social interactions, several strategies were mentioned:

''In former times, *I kept it under my hat* [Pf], right? Then, I did not, *did not say that I had something* [Pf].[…] today *I simply say it* [Pf], and then most likely *get up to move* [Pf] and say *I have problems with the legs* [b7650 Involuntary contractions of muscles] [patient with RLS].''

''Like, sometimes *you somehow put on a mask* [Pf], so that *you can actually get through life* [nd] [patient with sleep apnea].''

''…*I did not have my coming-out yet* [Pf], I just said *I must sleep* [b134 Sleep function]. *No one in the office* [e325 Colleagues] knows that I have this problem. *I am very open, I say: I am doing my power-napping – please do not disturb* [Pf]. *Some of them even approve of this* [e425 Individual Attitudes of Colleagues] [patient with narcolepsy]''

Generally, a major strategy and resource was 'taking time', developing positive sleep hygiene, and also balancing, controlling and planning daily activities.

''I always beg for time! [person with insomnia].''

''Every afternoon I sleep in the office, in my office chair – else I cannot manage [person with narcolepsy].''

''I always try and sleep on my side [patient with sleep apnea].''

''I work with to-do-lists […] If I have the liberty to do what I want, and can schedule my day accordingly, then I am doing relatively well. [person with insomnia]''

''…so that post-it's have become my best friends, I have simply just written down everything and somehow stuffed it in my pockets. [patient with sleep apnea].''

DISCUSSION

Based on the accounts of the lived experiences of persons with sleep disorders, the patients face severe activity limitations and participation restrictions, combined with impaired body functions especially around role expectations in work and private life. The interaction of the patient with contextual factors like family, work environment, individual and societal attitudes and the health system may act as act as barriers and facilitators.

Our qualitative data give evidence for the process of adaptation to a sleep disorder. This process is dominated by the experience of uncertainty before or during the time of diagnosis. This is accompanied by issues of legitimizing and explaining deviant behavior, unmet role expectations and falsely attributed symptoms, and leads to a process of reorientation after diagnosis. This process of reorientation is expressed in a transfer to tight sleep hygiene regimens, strict

Table 3 Fifty-seven second-level categories of component *Activities & Participation* (d): number of focus groups in which ICF categories (second-level) were mentioned by the participants; number of linkings across all focus groups

Activities & participation		*N**	*N*†
d110	Watching	4	17
d115	Listening	1	2
d155	Acquiring skills	2	2
d160	Focusing attention	3	3
d166	Reading	5	24
d175	Solving problems	1	2
d177	Making decisions	1	4
d210	Undertaking a single task	1	1
d220	Undertaking multiple tasks	3	5
d230	Carrying out daily routine	6	106
d240	Handling stress and other psychological demands	6	50
d310	Communicating with – receiving – spoken messages	3	6
d315	Communicating with – receiving – non-verbal messages	1	2
d330	Speaking	5	7
d335	Producing non-verbal messages	2	4
d345	Writing messages	1	2
d350	Conversation	5	11
d355	Discussion	3	5
d360	Using communication devices and techniques	5	6
d410	Changing basic body position	1	2
d415	Maintaining a body position	6	50
d430	Lifting and carrying objects	1	1
d435	Moving objects with lower extremities	1	2
d450	Walking	3	6
d455	Moving around	2	6
d460	Moving around in different locations	2	2
d465	Moving around using equipment	1	3
d470	Using transportation	4	28
d475	Driving	6	45
d520	Caring for body parts	1	2
d540	Dressing	2	3
d550	Eating	5	21
d560	Drinking	1	1
d570	Looking after one's health	5	40
d620	Acquisition of goods and services	4	15
d630	Preparing meals	6	14
d640	Doing housework	6	43
d650	Caring for household objects	3	14
d660	Assisting others	6	19
d710	Basic interpersonal interactions	5	22
d720	Complex personal interactions	4	15
d730	Relating with strangers	5	7
d740	Formal relationships	4	6
d750	Informal social relationships	4	12
d760	Family relationships	5	34
d770	Intimate relationships	6	30
d820	School education	3	7
d840	Apprenticeship (work preparation)	2	10
d845	Acquiring, keeping and terminating a job	6	33
d850	Remunerative employment	6	212
d855	Non-remunerative employment	6	26
d865	Complex economic transactions	2	5
d870	Economic self-sufficiency	3	11
d910	Community life	6	24
d920	Recreation and leisure	6	190
d930	Religion and spirituality	2	4
d940	Human rights	6	31

*Number of focus groups ($N = 6$) mentioning the respective ICF category.
†Number of linkings across all focus groups ($N = 6$).

Table 4 Forty-eight second-level categories of component *Environmental Factors* (e): number of focus groups in which ICF categories (second-level) were mentioned by the participants; number of linkings across all focus groups

Environmental factors		*N**	*N*†
e110	Products or substances for personal consumption	6	149
e115	Products and technology for personal use in daily living	5	47
e120	Products and technology for personal indoor and outdoor mobility	2	4
e125	Products and technology for communication	2	4
e135	Products and technology for employment	1	1
e150	Design, construction and building products and technology for public use	2	2
e155	Design, construction and building products and technology for private use	3	6
e160	Products and technology of land development	3	5
e165	Assets	1	3
e210	Physical geography	1	18
e225	Climate	5	27
e240	Light	3	21
e245	Time-related changes	4	25
e250	Sound	5	15
e260	Air quality	1	1
e310	Immediate family	6	168
e315	Extended family	2	5
e320	Friends	4	19
e325	Acquaintances, peers, colleagues and neighbors community members	6	79
e330	People in positions of authority	6	17
e340	Personal care providers and personal assistants	1	2
e345	Strangers	1	4
e350	Domesticated animals	3	7
e355	Health professionals	6	84
e360	Health-related professions	4	10
e410	Individual attitudes of immediate family members	6	96
e420	Individual attitudes of friends	3	16
e425	Individual attitudes of acquaintances, peers and colleagues neighbors	6	63
e430	Individual attitudes of people in positions of authority	3	16
e445	Individual attitudes of strangers	2	3
e450	Individual attitudes of health professionals	4	40
e455	Individual attitudes of health-related professionals	4	14
e460	Societal attitudes	4	32
e465	Social norms, practices and ideologies	5	22
e520	Open-space planning services, systems and policies	2	4
e530	Utilities services, systems and policies	1	2
e535	Communication services, systems and policies	3	4
e540	Transportation services, systems and policies	4	7
e545	Civil protection services, systems and policies	1	2
e550	Legal services, systems and policies	1	1
e560	Media services, systems and policies	2	4
e565	Economic services, systems and policies	3	4
e570	Social security services, systems and policies	3	19
e575	General social support services, systems and policies	1	1
e580	Health services, systems and policies	6	85
e585	Education and training services, systems and policies	2	4
e590	Labor and employment services, systems and policies	4	13
e595	Political services, systems and policies	1	1

*Number of focus groups ($N = 6$) mentioning the respective ICF category.
†Number of linkings across all focus groups ($N = 6$).

time management and self-control of daily activities. Our data suggest that persons affected by sleep disorders develop strategies (e.g. medication use, disclosure/concealment of diagnosis) and mobilize resources (e.g. family) in order to cope with the processes of adaptation.

When asked about their problems, patients rarely mention anatomical changes as represented by the ICF component Body Structures. However, (patho-)physiological changes, as represented by the ICF component Body Functions, as well as daily activities and participation in life, as represented by the

ICF component Activities & Participation, and Environmental Factors are reported by the patients as being important.

A huge spectrum of Body Functions was mentioned by the participants of the focus groups, covering all of the chapters of this component. The most frequently identified categories in the component Body Functions mostly belonged to the component's first chapter: Mental functions. These categories pertain to well-known impairments and symptoms of many sleep disorders, like cognitive functions (Ohayon, 2009; Panossian and Avidan, 2009; Rakel, 2009; Walker, 2009), mood (El-Ad and Lavie, 2005; Ford and Cooper-Patrick, 2001; Haba-Rubio, 2005; Hasler *et al*., 2005; Sateia, 2009), and sleepiness, tiredness or fatigue (Aguillard *et al*., 1998; Briones *et al*., 1996; Chervin, 2000; Hossain *et al*., 2005; Lichstein *et al*., 1997; Mathis and Hess, 2009; Reimer and Flemons, 2003; Roehrs *et al*., 2000; Schneider *et al*., 2004; Valko *et al*., 2008).

Aspects of the component Activities & Participation were also reported to be important factors in living with sleep disorders, affecting all life areas including mobility, self-care (e.g. sleep hygiene), domestic life and relationships. Predominantly, concepts linked around activities and participation were related to daily routine, work and private life, at time showing trade-offs between these major life areas (Basner *et al*., 2007). Research partly supports this finding in showing that combined with impairments on the level of body functions, work performance is limited (Barger *et al*., 2009; Bolge *et al*., 2009; Bultmann *et al*., 2005; Daley *et al*., 2009; Eriksen *et al*., 2001; Leger *et al*., 2006; Omachi *et al*., 2009; Rakel, 2009; Sivertsen *et al*., 2009; Sjosten *et al*., 2009). Altogether, there are no other comparative and comprehensive studies that account for the sum of factors we identified through our study.

Similarly, the interaction of the person and his or her environment remains scarcely researched. The relevant environmental factors we identified cover all chapters of this ICF component that range from treatment interventions like medication and assisted ventilation, circadian elements represented by the natural environment, to aspects of the work environment. In our sample, patients mostly related to categories of chapter 3: Support and relationships of the ICF component on environmental factors, and also their engagement with health services and health professionals.

Emerging research supports the importance of including the patient perspective through comprehensive and multidisciplinary designs. Especially in pediatrics, models have been developed that seek to understand the interdependence of sleep, behavior, the family, and the physical and social environment (Beebe, 2008; Brand *et al*., 2009). The critical importance of social support and possible conflicts arising from families seeking to cope with disability have been stressed (Ell, 1996).

Explorations into behavioral correlates with adherence to continuous positive airway pressure treatment (CPAP) in patients with sleep-related breathing disorders further stress the importance of including the patient perspective holistically (Broström *et al*., 2010). Whereas it seems that personal factors like self-efficacy before contact with the health system do not predict CPAP post-treatment, the patient perception in the first week of treatment accounts for about 20–30% of the variance in CPAP use (Weaver, 2005; Wild *et al*., 2004). The narratives of our patients stress the importance of the initial clinical encounter, and how the interaction with health professionals is critical for them. The reports of negative experiences with health care providers that are not trained in treating and diagnosing sleep disorders (Papp *et al*., 2002), or wrongly diagnosing these patients, and suggesting different treatment options (Buysse *et al*., 1997; Chokroverty, 2003; Kapur *et al*., 2002) are evident based on our study. The importance of education, caregiver relationship and social networks, however, remains underestimated (Aloia, 2009; Broström *et al*., 2009; Collins *et al*., 2007; Ell, 1996; Vourlekis and Ell, 2007). Our study added further evidence to support the interrelation and importance of the factors mentioned earlier.

About a quarter of our ICF linkings were coded as personal factors. This stresses the importance of the individual or personal context variation in living with sleep disorders that also include important aspects of psychosocial factors, resource management and strategy development. Unfortunately, Personal Factors cannot be coded like the other components in the ICF model. ICF broadly suggests that Personal Factors may comprise factors like gender, race, age, lifestyle, habits, coping styles, education, past and current experiences, behavior patterns, character style, and psychological assets (WHO, 2001, p. 17). However, the authors of the ICF and other institutions like the Institutes of Medicine (IOM, 2007; Whiteneck, 2006) have stressed the importance of personal factors, and have suggested to structure and classify them (Heerkens *et al*., 2004; Stephens and Kerr, 2000; Ueda and Okawa, 2003; Viol *et al*., 2006, 2007).

Nevertheless, some interesting findings on Personal Factors could be detected. One of many such examples for Personal Factors is the problem of the visibility of the disability experience associated with sleep disorders. In this context, subtle differences in self-perceptions between the diagnostic groups could be detected, for example the insights related to legitimizing and justifying the disorder offered by this obese female person with sleep apnea as she responded to a person diagnosed with narcolepsy:

> There are decent and indecent diseases, you [addressing the person with narcolepsy] have a decent one. If I wasn't overweight, I could point out clearly that I am not responsible…

Relating to the diagnostic group of narcolepsy, which were predominantly represented in our sample, further insights into their coping style and behavior patterns could be detected. Given the degrees of uncertainty after onset of symptoms (Lorence and Hummel, 2006), before and after diagnosis (Broughton and Broughton, 1994; Wilson *et al*., 2007), and the chronic nature of narcolepsy, this patient group seems to be overtly challenged to develop distinct strategies of coping with a disorder that is not directly visible in the interaction with the

environment, but more evident through performance-related problems than other sleep disorders (Bayon *et al*., 2009; Schneider *et al*., 2004; Teixeira *et al*., 2004). Analogous to findings in epilepsy (Faircloth, 1999; Schneider and Conrad, 1981), we were able to distinguish typological behavior in social encounters and in disclosing or hiding the disorder, ranging from a secretive to a pragmatic type selectively concealing their disorder, to a quasi-liberated type that naturally confronts others with their health condition.

Our study has several limitations. From these findings it cannot be concluded that the encountered functional problems are equally relevant and representative for all sleep disorders or all people living with a specific sleep disorder. The rather less clinically prevalent sleep disorders, for example parasomnias and circadian rhythm sleep disorders, are not represented in our sample. The predominance of diagnoses of narcolepsy and sleep-related breathing disorders in our sample may have further biased our finding towards functional problems related to the leading symptoms of hypersomnia or sleepiness within these groups. Neither is this study taking into account cultural variation (Bliwise, 2008), using German-speaking participants in Switzerland. Sleep disorders often develop in the early years of age and, by excluding persons below the age of 18 years, specific aspects of age-related issues could only be detected through retrospective reflections and narratives of our participants. These must be considered major limitations, and further qualitative studies with different diagnostic groups in different parts of the world would be desirable.

The number of focus groups in which a specific problem was mentioned and the frequency with which this problem was accounted may provide an impression about the relevance of a problem. In addition, one might argue that the questions in the topic guide are leading in nature and that several participants of one and the same diagnosis might have dominated the topics discussed in one focus group. However, as documented in the research diary, participants tended to freely diverge from the direction given in the open-ended questions. They appeared to follow a hierarchy of degrees of current or recollected suffering, and this degree of freedom stimulated the interaction between all participants. Above all, it is essential to take into account that the qualitative methodology used in this study was aimed at identifying the broadest possible range of problems. This was also done in order to provide – along with another patient study using semi-structured interviews and a larger sample – a decision base for the consensus process in the development of ICF Core Sets for Sleep Disorders (Stucki *et al*., 2008). The determination of the prevalence of problems for the separate sleep disorders or different etiopathologies needs further investigation using mixed methods and comprehensive designs.

CONCLUSION

This study provides evidence on the importance of comprehensive conceptualizations applying qualitative methodology, and helps to holistically understand and address the impact of sleep disorders based on the bio-psycho-social model of the ICF. Following the principle 'nothing about us without us'(UN, 2006), the data we gathered directly from the patient perspective would serve as a basis to develop and adopt international standards for comprehensively describing the functioning in individuals with sleep disorders.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Figure S1. The current framework of functioning and disability – the WHO International Classification of Functioning Disability and Health (ICF).

Figure S2. Structure of the International Classification of Functioning Disability and Health (ICF) classification. Hierarchical structure of the ICF (WHO, 2001; the figure has been reprinted with permission of the WHO, all rights are reserved by the Organization).

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